



Hermeneutic phenomenological interpretations of patients with head and neck neoplasm experiences living with radiation-induced xerostomia: The price to pay?



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A B S T R A C T

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Purpose: Patients with head and neck neoplasms often experience a number of persistent treatment related symptoms including xerostomia. The impact of xerostomia can be profound and wearing on the patients, hence negatively influencing their quality of life. The purpose of this study was to explore the in-depth experiences of the patients living with radiation-induced xerostomia.

Methods and sample: This was a hermeneutic phenomenological study inspired by the Philosophy of Paul Ricoeur. Research data were retrieved with individual narratives from 15 patients diagnosed with head and neck neoplasm that underwent radiotherapy.

Interpretation proceeded through three phases: naïve reading, structural analysis and comprehensive understanding.

Results: Five themes consisting of ten sub-themes emerged from the narratives reflecting on the patients' lived experiences. The themes were "suffering of the body", "suffering of the person's world", "being helpless against xerostomia", "suffering of the mind" and "being alone". The comprehensive understanding disclosed new possibilities for *being-in-the world* in relation to living with xerostomia.

Conclusion: The precedent consideration of xerostomia mainly as a physical side-effect of radiotherapy was outweighed by the social and psychological effects revealed by this study. These xerostomia's effects are inflicted on the patients with an obvious reflection on their perceived quality of life. The findings call upon a shift towards acknowledging the severity of xerostomia and the need to care for these patients holistically.

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Introduction

Xerostomia is generally accepted as the subjective complaint of a dry mouth, which is correlated with objective findings of salivary gland dysfunction. The word xerostomia derives from the Greek word ξηροστομία, which is made up by two distinctive words dry (-ξηρός) and stomia (-στόμα), which refers to mouth (Stedman's Medical Dictionary for the Health Professions and Nursing, 2011). The etiology of xerostomia varies and includes radiotherapy, a treatment that has been at the forefront of treating head and neck

neoplasms. Head and neck neoplasms respond well to the radiotherapy treatment which is evident in the high percentage of remission or complete cure recorded. However, radiotherapy is in many cases accompanied by moderate to severe side-effects. Explicitly, a large number of oral side-effects (i.e toxicities) have been attributed (primary or secondary) to radiotherapy including xerostomia (Porter et al., 2004), mucositis (Guggenheimer and Moore, 2003), taste alternations (Cooper et al., 1995; Lundy and Sullivan, 2012), difficulties with mastication and deglutition (Eisbruch et al., 2003) and orofacial changes (Folke et al., 2009), just to report a few.

In the literature, the biomedical aspects of xerostomia have been well described (Ship, 2002). In recent years the understanding of xerostomia's pathophysiology (Bajjal et al., 2012) and its clinical course (Vissink et al., 2003) in the context of radiation therapy has significantly improved (Bhide et al., 2009). Serous acini, found

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predominantly in the parotid glands, are the main contributors of stimulated salivary flow and appear to be particularly susceptible to radiation damage (Chambers et al., 2007). Therefore, irradiation results in the parenchymal tissue of the salivary glands are to be characterized by low mitotic activity. The reproductive death as a result of the DNA damage is unlikely during and shortly after radiation. Acute inflammatory infiltrates parallel degenerative changes in parenchymal cells 24 h after a single radiation dose. After a high radiation dose, the degenerative changes progress over time and the glands atrophy and become fibrotic. As a result, saliva becomes more viscous and ropy and is diminished in quantity.

Background

The efforts to find a cure or an effective management for xerostomia have been unsuccessful. The suggested conventional and complementary and alternative (CAM) approaches are ineffective in providing a comprehensive management of xerostomia and its subsequent effects (Chambers et al., 2007). Therefore, an increased number of people are forced to live with this side-effect during the treatment and soon after its completion. However, for some patients the xerostomia will endure long after the treatment and it can affect them for the rest of their lives. This is the case when the salivary glands are permanently damaged by radiation and saliva replacement agents are not tolerated by the patient (Gornitsky et al., 2004; Haddad and Karimi, 2002). Furthermore, the lasting effects of xerostomia can also arise when the pharmacological agents are accompanied by severe side-effects minimizing adherence and lead to disruption of treatment (Brizel et al., 2000). Permanent xerostomia is the most prevalent late side-effect of irradiation for head and neck neoplasms (Eisbruch et al., 2003).

Three qualitative studies (Wells, 1998; Larsson et al., 2003; Folke et al., 2009) shed some light on this experience from the patient's perspective. Wells (1998) in a naturalistic inquiry explored the experiences of 12 patients that had undergone radical radiotherapy to the head and neck region and experienced various radiation induced side-effects including xerostomia. The study emphasized on the period that followed the completion of radiotherapy when the treatment's side-effects were at their peak and day to day links with the hospital were severed. Data were collected with unstructured interviews additionally to patients' personal diaries that patients. The impact of radiotherapy and the profound disruption to daily life was shown by the uncertainty and unpredictability of symptoms, the waiting, ambiguity and loss of self-integrity which occurred throughout this time. Despite considerable physical and emotional trauma, patients showed remarkable resilience and a profound reluctance to ask for help.

Larsson et al. (2003) in an interpretive phenomenological study explored the experiences of patients diagnosed with head and neck neoplasms in relation to eating problems during radiotherapy. Eight patients were invited in an open interview during the time of radiotherapy (2–3 weeks after the first radiotherapy session). In their majority the patients were diagnosed with radiotherapy-induced xerostomia. The patients perceived xerostomia as one of the main reasons that limited their ability to chew and swallow and also limited their will and desire to eat. This study identified the need to view eating problems as a complex phenomenon in a specific context including the individual patient's life situation.

Folke et al. (2009) in a qualitative study explored the main concern of xerostomia as it was expressed by afflicted adults. Interviews were conducted with 15 participants and analysed with the grounded theory method. Folke et al. (2009) did not specify whether the patients were diagnosed with head and neck neoplasms or whether they were subjected to radiotherapy and

developed xerostomia as a side-effect. The analysis identified "aggravating misery" as the core category. This category reflects the major concerns expressed by the patients that relate to the devastating and debilitating impact of xerostomia on multiple domains of their well-being. "Professional consultation", "search for affirmation" and "social withdrawal" were the management strategies that patients used in order to cope with the effects of xerostomia.

The relevant literature has emphasized on the physical effects of xerostomia whilst the literature on the psychosocial dimension of the topic is scarce. The way patients experience the impact of xerostomia on their every day lives remains partially described, revealing an apparent gap in the relevant literature. The studies reviewed above showed that radiation-induced xerostomia can have a profound and wearing effect on a person that can negatively influence his or her general well-being. This reveals that xerostomia is not a trivial condition for those suffering it. The insufficient attention to this side-effect can be partially attributed to the fact that xerostomia is not classified as a life threatening side-effect (Taweekhaisupapong et al., 2006). Managing this side-effect is an important task that merits concerted research to understand how to better and more effectively support the patients.

The aim of this hermeneutic phenomenological study is to provide an insight as to how the patients themselves face, experience and attribute meaning to living with xerostomia with emphasis placed on the psychosocial effects of radiation-induced xerostomia.

Methods

Design

This was a hermeneutic phenomenological study inspired by the ideas of the French philosopher Paul Ricoeur. Hermeneutic phenomenology is consistent with the nursing paradigm that views the person as one who is constantly interacting with the environment, interpreting impressions and ascribing personal meaning to the experience.

The process of unveiling the narrated experience is based on Ricoeur's interpretation theory that is underpinned by the concepts of distanciation, appropriation, understanding and explanation (Fig. 1). These concepts, although playing an essential role in the interpretation of the text, remain invisible to the reader who is able to identify only the new appropriated meaning of the text; the new ways of *being*. The subjective nature of the experience is celebrated by the nursing paradigm and echoes Ricoeur's notion of "polysemy" namely the fact that there can never be one universal truth.

The appropriateness and compatibility of these ideas in nursing are evident in the relevant literature that shows a considerable number of nurse researchers have successfully applied the philosophical ideas of Paul Ricoeur as a methodological and theoretical framework (Tan et al., 2009; Dreyer and Pedersen, 2009; Charalambous, 2010).

Settings

Patients were recruited at the two out-patients clinics of a specialized cancer care centre in Cyprus; a centralized centre where patients receive specialized treatment for Head and Neck neoplasms. Patients are referred to this facility from cancer care clinics (public and private) from all over Cyprus. Patients were referred to these clinics in order to treat various radiotherapy-induced side-effects.

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